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Vulnerability and Children with Disabilities: Ethical Spheres of Concern in Research and Practice

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Vulnerability and Children with Disabilities

Chris Kliwer & Susan Etscheidt

Ethical Spheres of Concern in
Research and Practice

Ethical Ideals

- Autonomy
- Beneficence
- Justice

Proposition 1

- The traditional utilitarian approach to research and practices that involves weighing the value and benefits of research and practice against the possible costs or harm to the participants may be **insufficient** to achieve those ethical ideals.

Proposition 2

- A conclusion that we have met our ethical obligations through an initial, contractual agreement to obtain parental consent and child assent may **obscure** the ethical complexities that we encounter as we sustain interaction with students with disabilities in research and practice

Proposition 3

- The attribution of children with disabilities as a homogeneous, vulnerable, need-to-be-protected, group may inadvertently **restrict** the child's active and self-determined involvement in research and special education practices.

Origins & Interpretations of Vulnerability-Protection

Ethical Violations in
Medical &
Social-Behavioral Research

Tuskegee Syphilis Study

(1932-72)

Jewish Chronic Disease Hospital Study (1963)



Hornblum, A (2013) NYC Forgotten Scandal

<http://nypost.com/2013/12/28/nycs-forgotten-cancer-scandal/>

U.S. Army LSD Studies (1955-72)



**NPR: Found In The Archives:
Military LSD Testing**
December 01, 2010

Milgram Authority/Conformity Study (1961)

Willowbrook Study (1956-72)

NPR: Remembering an Infamous New York Institution

March 07, 2008

U of Iowa Stuttering Studies (1939)

.

Dyer ((2001). Ethics and Orphans: The Monster Study.

<http://webmedia.unmc.edu/alliedhealth/pbottjen/Ethics%20and%20Orphans.pdf>

Belmont Report (1979): Ethical Principles and Guidelines for the Protection of Human Subjects of Research

■ Respect for Persons

- individuals have **autonomy** and **choice**
- people can not be used as a means to an end
- provide protection to the **vulnerable** [fetuses, pregnant women, human *in vitro* fertilization, **children**, prisoners, or **subjects who may have diminished capacity**.
- provide informed consent and privacy

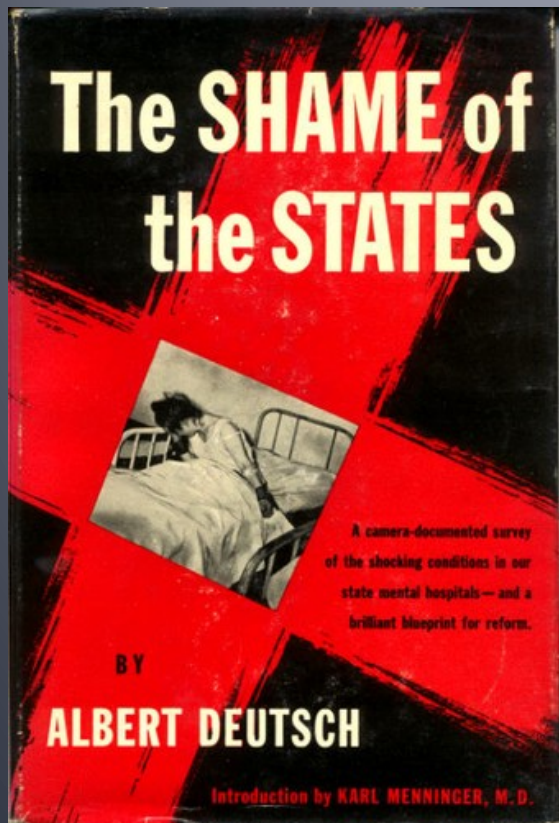
■ Beneficence

- minimize risks, maximize benefits
- obligation to do good
- obligation **to do no harm**
- obligation to prevent harm
- basis of risk/benefit assessment

■ Justice

- treat all fairly
- share **equitably** burdens and benefits
- Selection not based on convenience

Origins & Interpretations of Vulnerability-Protection



Abuse, Neglect & Exclusion of Children with Disabilities

Pictures from: Deutsch, A. (1943). Shame of the States.
New York: Hartcourt, Brace.

Institutional Response

Eugenics Movement

Segregation

Separate but Equal

Special Schools

Disability History Museum:
Permissions for Limited Use
<http://www.disabilitymuseum.org/>

Special Classes

Testing & Placement

Self-Contained

The Education of All Handicapped Children Act (EAHCA) (1975)

- Findings:
 - 8 million handicapped children in the US
 - More than 1/2 do not receive appropriate educational services enabling full equality of opportunity
 - 1 million are excluded entirely from public school system
- Purpose:
 - To assure all handicapped children have available to them a Free Appropriate Public Education [FAPE]
 - To assure & protect the rights of handicapped children & their parents
 - INITIAL PARENTAL CONSENT & CHILD INVOLVEMENT

Regulatory Protections for Vulnerable Children

only “touch the hem of the ethical garment”

[Vanderpool, 2002, p. 3]

Respect for Autonomy

- ? achieved when parental permission and child assent are obtained via **signed contracts** prior to conducting research or providing special education services?

Beneficence

- ? attained when the researcher promises to do good and not to harm? ? when s/he claims to maximize benefits and minimize harm?
- ? evidenced when the practitioners address academic & behavioral **deficits due to a disability?**

Justice

- ? met with **compliance** to the laws and regulations?
- ? with duties to report adverse events?
- ? or with opportunities for Ps to file complaints satisfy the duties to assure justice?

Proposal: Parental Permission and Child Assent Must be Sustained

Revisiting Child Assent In Research

Presumptions

- The “all-too-common erasure of volition for children” [Gallant, 2002] – particularly children with disabilities – should be replaced with a **presumption of competence** to assent.

Sustained Assent

- Reflexive, development nature of research w/ children requires **on-going agreements** not initial permission [Lawton, 2001] - negotiated throughout the research process [Smith & Murray, 2000]

Quote: Constant Vigilance

- “Seeking assent requires the researcher to remain **constantly vigilant to the responses of the child at all times**: it is not something gained at the beginning of the research then put aside. It requires time and constant efforts on the part of the researchers, who need to attune themselves to the child’s unique communication in order to know when to remove themselves” (Cocks, 2006: 257-258).



Underestimating

- Children NOT passive [vulnerable, powerless, incompetent] but competent, active & capable [Farrell, 2005; Danby and Farrell, 2005]
- Underestimating a child's capacity to consent = **inconsistent with principle of respect for autonomy** [Stanley & Sieber, 1992].

Continuous Verification

- The inability to know or anticipate risks – coupled with the duty to remain faithful to promises and commitments [veracity] - requires continuous verification that benefits to the student are accruing and that s/he wishes to continue to participate.

For research...

- **Intermittent checks** inform the PI of P or child's wish to continue to participate or to stop or withdraw.
- Checks remind the P and child that participation is voluntary & refreshes the purpose, benefits and risks

Age & Variables

- Rather than age as an index of capacity for consent, consider **variables**: the nature of the interaction, context, and tasks [Thompson, 1992]
- Consider how the **child's disability** may affect soliciting on-going assent
- What to share depends on those variables: perhaps purpose, time, who will know the results, confidentiality (Dockett and Perry, 2007).

Conceptualizing Assent

- PIs should conceptualize assent and dissent as important, independent ethical constructs that should be defined broadly and assessed by how the child can express or indicate their preferences verbally, behaviorally, or emotionally [Dobson, 2008].

Sustained Respect

- For children with significant disabilities, it may be difficult to explicitly gain assent...so Pls must give priority to **showing respect** for the children throughout the process (Johansson, 2003).

Presentation

- Q & A: to “genuinely inform”
= Dialogue not signatures
[Pomerantz & Handelsman, 2004]
- “Accessible language”, using
an interpreter or reader of
written information

Provision

- Information provided in **alternative formats** [aural for Ss w/ visual disabilities], **visually-cued formats** [pictures, graphics, diagrams, color] or **behavior-based formats** [models, dramatization].

Consultation

- Other options might include interpretation of child responses by **those most familiar** with the child [family & FRIENDS]
- Consulting with others **safeguards the inclusion of children whose capacity to assent might be limited.**

AAC Possibilities...

- Consider **alternative or augmentative communication options**, symbolic representations, and talking mats [Cameron & Murphy, 2006].

Issues of Coercion

- **Power asymmetries** present ethical issues in research with children...
- Children may find it **hard to say no** to adults (Backe-Hansen, 2002)
- Children may be too afraid or confused to refuse (Alderson and Morrow, 2004).

School Settings

- Children lack maturity or independence to decline participation when **dependent** on PIs for grades, resources and enriching school experiences.
- Ss may feel unable to dissent since most activities are **compulsory** (Morrow and Richards, 1996).
- Child decisions based on **desire to please** (*Heath et al.*, 2007) or a **fear** of potential consequences.

Informed Dissent

- Ss must know P or T or PI **not “mad”** if refuse or stop
- Abramovitch (1991) found children thought PIs or Ts would be upset if they refused or stopped.
- If they know their Ps agree, thought P might be upset if dissenting.
- Bruzzese & Fisher (2003) found that children did not know **HOW** to withdraw, dissent or decline.

Show and Tell

- Ss must know HOW to dissent: give Ss **specific examples** of how to decline
 - stop sign, walk to door, raise hand, control of recorder

Signs

- Pls aware of indirect, subtle signs children no longer wish to participate [Kay, 2002].

Concluding Thoughts: Autonomy in Research

- A **presumption of competence** should preserve volition of children in research
- Autonomy should shift from utilitarian “recipient” to include free action (no coercion), **authenticity** (consistency with values -presumed); effective **deliberation** (weighing w/all info); and **moral reflection** (self-analysis & introspection) [Haverkamp, 2005]

PROPOSAL: The application of “nothing about us without us” should guide educational practices for children with disabilities

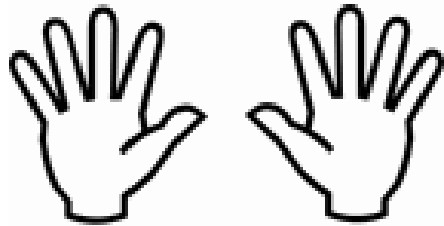
Revisiting Child Assent in Practice

- The narrow cost-benefit approach of the utilitarian approach has also deeply influenced the trajectory of special education and practice through so-called gold standard approaches involving Applied Behavior Analysis and adaptive skill development through means such as social scripting.

Quiet Hands

[I Will Not Have Quiet Hands \(poem\).](#)

Available at: <http://autisticadvocacy>.



Quiet Hands

Traditional Disability Research

- Using the cost-benefit approach, traditional research has often been **done 'on' or 'to'** people with disabilities, by non-disabled researchers (Radermacher, 2006)
- It has been described as parasitic, alienating, unrepresentative and exploitative (Olcay, 2001).

“Nothing About Us Without Us”

requires political-economic and cultural systems to incorporate people with disabilities into the decision-making process and to recognize that the experiential knowledge of these people is pivotal in making decisions that affect their lives” (Charlton, 2000, p. 17).

More than a slogan...

- Application to research with children “provides a **complex and extremely challenging task...** turning rhetoric into reality entails seriously addressing such questions as ‘What form should research take?’, ‘**What sort of partnership does this involve?**’ [Barton, 2005]

Emancipatory

- Any costs or risks to Ps are relative to discerning abuses and oppression of marginalized groups.
- The research is ethical by nature of the advocacy and resulting liberating benefits.

Disability Research

- Participatory, emancipatory disability research is characterized by **partnership** with individuals who have the disability being researched.
- The goal is to provide greater opportunities for people w/ disabilities **to be involved** with research and requiring non-disabled researchers to take a **reflexive** approach & be **accountable** to these participants as co-researchers.

Impact

- Barnes (2003) argued that emancipatory disability research had made a significant impact on society through empowerment in process and outcomes

Partnerships

- This emancipatory approach recognizes the need to establish a **workable dialogue** between the research community and disabled people who understand the process of disablement (Barnes, 1992)

Utility

- Disability research that is driven by people with disabilities is likely to actually be useful [Arnold, 2010]

Covenantal

- Similarly involves an **exchange or agreement** between Pl and Ps, to improve the future for both: “a reciprocal and authentic exchange ...that **transcends conventional notions of contract**” (Newton, 2009).
- A responsibility and ethical demand to act in the best interest of our fellow human beings” (Hilsen, 2006, p. 27) – interdependency & cogeneration of knowledge

Teacher Action Research

- Often cited as an example of this mutual-benefit approach.
- Challenge = the notion of a “reciprocal and authentic exchange” between researcher and participants

How? Quote

- What are the processes that a teacher and her or his students can use to collaboratively develop a teacher research question that focuses on the teacher's practices while meaningfully including students as partners in the action research? Brydon-Miller, M., Coghlan, D., Holian, R., Maguire, P. & Stoecker, R. (2010).

- Questions??
- Comments??
- Discussion??